Abstract

The majority of people with degenerative neurological conditions are cared for within their own families. Cognitive impairment can be a significant and increasing symptom of these conditions. In this article we report how a team of experienced researchers carried out a meta-ethnography of qualitative research articles focusing on the impact of caring for a loved one with cognitive impairment. We followed the seven step process outlined by Noblit and Hare. Findings suggest emotional impact is complex and uncertain. The impact can be both positive and negative and can vary from day to day and considerably over time. The benefit of using meta-ethnography is that the results represent a larger sample size and a re-interpretation of multiple studies so can hold greater application for practice.

Key words. caregiving; informal; coping and adaptation; families, meta-ethnography; qualitative analysis;

INTRODUCTION

Neurological diseases affect 200,000 people in the UK alone (Fitzpatrick *et al*, 2010). Across the Western world, as treatments improve and the population ages, attention is being focussed on rehabilitation and social care to improve quality of life for both those directly affected and their carers (Bartollo *et al.,* 2010; Myashita *et al*., 2011). The range of services needed is challenging and requires a multidisciplinary approach. In a recent report by the UK Department of Health (DH) (*Recognised, valued and supported: Next steps for the Carers Strategy 2010*) the essential role of carers was emphasised and a range of measures was put forward to support carers, such as respite and psychosocial support. However a greater understanding of the psychological effect of caring for a loved one with decreasing cognition and erratic behaviour will offer health and social care service workers a context in which to plan appropriate services and monitor changes over time.

The continual exposure to chronic psychological stressors, created by caring for loved ones with psychological impairment, has been shown to be deleterious to the carees health (Stephens, *et al*., 1991; Tooth et al., 2008). In a meta- analysis conducted by Martire *et al*. (2004) the authors considered how psychosocial interventions affected individuals and families and found that whilst there was some positive response to professional help the positive effect was more likely to be effective in situations where there was no neurological impairment. Vitaliano *et al*. (2003) conducted a quantitative synthesis of studies which considered the effect of caring on the carer's health compared to non-caregivers. They found that caregivers had a 23% higher level of stress hormones than did non-caregivers. Their concern was the clinical implications of providing increased medical care to informal carers of people with long-term conditions.

The impact on carers of prolonged emotional stress due to providing physical care to a caree with a neurological condition has been well documented (Corry & White, 2008; McLaughlin *et al*. 2010). Of importance is the need for a qualitative understanding of carers' experience, their greatest areas of concern and their day to day pressures. Meta-ethnography provides an opportunity to critically appraise existing qualitative literature focusing on the emotional impact of caring for someone with decreasing cognition. Synthesizing across multiple studies can provide a greater clarity and understanding about the issues the studies identify to be important and relevant**. In turn, there is a greater potential to inform practice, allowing health and social care workers to consider how best to support carers of people with neurological conditions.**

AIM

This study had two aims: 1) to utilize the findings of published qualitative research, specifically related to neurological conditions, to develop a deeper understanding of the impact of cognitive impairment on the carer and to find areas of concordance across four of the most common neurological diseases, and 2) to provide a worked example of a meta-ethnography

METHODS

Meta-ethnography

The aim of meta-ethnography is to ensure that the findings of relevant studies are systematically compared, rather than aggregated (Sandelowski & Barroso, 2007). Like all qualitative endeavor, meta-ethnography is used to find meaning in the context and experience of participants. Relevant research reports are identified and through translation of the concepts or metaphors (similar to the constant comparison of a grounded theory approach (Strauss & Corbin, 1990), the findings of the studies are synthesized. Unlike meta-synthesis the document search is not all inclusive but purposive enabling 'interpretative explanation'

rather than prediction (Doyle, 2003). Where accounts are not in agreement, an alternative view of the findings may be put forward. Following analysis and synthesis of all the data 'a line of argument' is developed which reflects the findings of the multiple studies but also offers a greater understanding and depth to the subject under study (Noblit & Hare, 1988). The "line of argument" includes the process of reaching new interpretations or presenting the findings from multiple studies in an accessible format in order to understand a particular phenomenon better (Sandelowski, 2004: 1357)

Synthesis of data from a range of studies has the potential to deliver a more comprehensive understanding of the question under consideration than the results from only one study. Zimmer (2006) and Doyle (2003) highlight the importance of meta-ethnography to praxis enhancing the results of research so that their value to policy makers is recognized. Thorne *et al*. (2004) interviewed experienced qualitative researchers all of whom had conducted meta-ethnography. Whilst generally excited by this method of working with a range of research study results, their concern was that there should be clarity and consistency about the approach and an awareness of the reality of what this approach offers. One of the researchers suggested that meta-ethnography is a method which increases knowledge (Jenson 2004: 1346). What is fundamental to meta-ethnography is, as with all qualitative research, the methods used to achieve this new understanding are transparent and clearly explained.

This study uses an adapted process which was originally described by Noblit and Hare (1988).

1. Getting started: deciding on question to be answered
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another

6. Synthesizing the translations
7. Expressing the synthesis

The meta-ethnography was conducted by a team of senior researchers. One researcher took responsibility for the overall management of the task and the other members of the team worked in accordance with the agreed procedure. The team consisted of two professors and three post-doctoral researchers who were all experienced in qualitative health and social care research.

Literature search

The research question: What is the emotional impact of caring for someone with increasing cognitive impairment?

Inclusion criteria

Decisions about the methods used in the research strategy were based on previous work undertaken by Campbell *et al*. (2003), Malpass *et al*. (2009), and Smith *et al*. (2005). The focus of the inclusion criteria was to find qualitative literature, in English, which described the impact of cognitive impairment on carers across four of the most common neurological diseases Alzheimer, Parkinson, Huntington disease and Multiple Sclerosis. **We felt choosing the most common diseases would provide us with sufficient data particularly as these four neurological diseases can produce symptoms of cognitive impairment.** We limited the time from 1990 onwards when the role of carers moved higher up Western Government agendas in response to aging populations and therefore prompted a wider range and greater depth of research articles.

- Qualitative research analyzed using qualitative methods and presenting qualitative data;

- Research about people with Parkinson and Huntington disease, Alzheimer and Multiple Sclerosis. This was refined to add Dementia as a precursor to or occasionally used to describe Alzheimer disease;
- Research examining the psychosocial impact of the disease on carers;
- Articles published in English;
- After 1990.

Search words and data bases

As the aim of the meta-ethnography was to understand the emotional impact of cognitive impairment we used search words which would reflect our focus. These included broad definition words such as "cognition" which would offer us a profile of the issues related to organic decline. We then chose words which indicated the emotional impact on carers such as "stress" and "burden" and then included words which would indicate change in carer experience such as "empowerment" and "change".

- Multiple sclerosis, Huntingdon, Parkinson, Alzheimer (and dementia)
- Cognitive, cognition, cognitive impairment,
- Strain, impact, burden,
- Caring, care givers, care
- Spouses, significant others family,
- Empowerment, change, independence, attitudes, perceptions

We used the following electronic databases: Medline; Psych Info; Amed; ASSIA; Swetswise,; CINAHL (plus) and Science Direct. We then contacted relevant experts in the field to ask about possible sources we may have missed and the research team reviewed their own databases for appropriate literature.

A total of 14,321 citations were filtered and 14,265 were rejected based on the title and abstract (Table 1). Fifty-six full texts were ordered for a more detailed review. Two

researchers read all except three texts which were not available by the study cut off date. Two of the fifty six were found to be duplicates. Thirty seven articles appeared to meet the inclusion criteria as agreed by both researchers.

INSERT Table 1 about here

Critical Appraisal

Thirty seven articles were randomly divided amongst the research team for further screening to assess their suitability for inclusion in the synthesis. One of the researchers analyzed all articles, and the other four analyzed a sub-set therefore all articles were appraised by two researchers. A critical appraisal tool (Dixon-Woods, 2004) was used to assess the quality of the articles in order to screen them for their suitability. Various opinions have been put forward in the literature for the benefit of using appraisal tools when assessing qualitative articles for inclusion in a meta-ethnography (Chapple & Rogers, 1998; Barbour, 2001). The debate centers around whether an article that does not provide a clear audit trail of the methods used to reach the results should be excluded from synthesis. However the restrictions of some journals on word limitations may preclude full disclosure of methods, thus making assessment of validity difficult for a second reviewer. One method of addressing this is to contact the original researchers in person. We were prepared to do this had it been necessary. However, following lengthy discussion within the group it was decided that we would use the Dixon-Woods (2004) appraisal criteria to rate the articles and assess whether the research articles had as she suggests: a clear research question, was qualitative research, and the context, sampling, data collection and analysis were described. Subsequently a decision was made not to contact original researchers.

Following this appraisal process six articles were rejected as being inappropriate for further analysis. Three of the six were excluded because they did not report research findings, two were excluded because the methodology reported was confused and the last one was excluded because it reported the impact on service provision rather than the emotional impact on carers.

The data extraction process

Of the thirty one remaining articles, seventeen focused on Alzheimer, four with dementia, two with Huntington, four with Parkinson and four with multiple sclerosis. Three articles were reviews of parts of larger studies. In twenty three studies the authors used semi-structured interviews and in one an open-ended interviewing technique. Five studies reported the use of focus groups and one study used internet messaging as a method of gathering qualitative data. The age range of the carers (where they were mentioned in the studies) was 18-86. The population groups for the studies ranged from couples, family caregivers, spousal caregivers and a caregiving son and daughter.

Table two provides an example of the initial data sheet used by all members of the research team to describe their articles. Initial extraction involved describing the research in terms of aim, sample, method and so forth and then identifying the direct patient quotes and the themes created by the original researchers.

Each team member recorded, where reported, the categories developed by the authors of the original papers from their raw data. They then recorded the final themes developed by the original authors to explain their findings (Britten *et al*. 2002).. The completed tables were then used as a basis for initial discussions amongst and between team members as we began the process of critical appraisal to develop our understanding of the emotional impact of cognitive impairment .

INSERT Table 2 about here

Synthesis

The next stage of the meta-ethnography as described by Noblit and Hare (1988) is to use a constant comparison technique across all the papers to identify areas of concordance and difference to develop a new or deeper interpretation of the findings. This process is little different from other qualitative methods, such as grounded theory, but in this instance the secondary data are treated as primary data (Malpass *et al*. 2009).

Britten *et al*. (2002) emphasized the need, at this point, to maintain the original meaning of the constructs both within and across articles. The research team met again and discussed each of the articles in depth. Similar ideas were identified across the articles and we began to develop a framework for the constructs. The process was iterative, the team members discussed the findings from the articles and used different methods such as mind maps, charts and lists to identify causal relationships and increase understanding. These visual schemes began by being a simple identification of emotional impact words and phrases but became better developed by adding arrows and links between ideas generated through discussion and further analysis of the articles. Eventually we identified similar words such as frustration, anger and impatience which described the essence of the emotional impact of caring.

Translation

The process of translation is an essential facet of the meta-ethnography method. Turner (1980) suggests that translation is "social explanation". The process should allow ideas and understanding to emerge that maintain the integrity of the original researchers' categories but increase social understanding of the phenomenon under study. As table three shows words which had been identified as common across many of the papers were placed next to the participants own words. A comparison of how and why the words had been used enabled us

to begin to understand the emotional impact of cognitive impairment from the carer's point of view. Sandalowki and Barroso (2007) suggest grouping the findings about the same topic not findings that say the same. This, therefore, involved choosing quotes that refuted or extended the developing ideas, allowing us to begin to understand the different relationships between the emerging constructs and ensure we monitored our decisions. We agreed final interpretations by consensus after this exhaustive process.

INSERT Table 3 about here

Synthesising translations.

As the tables and diagrams became more sophisticated we discussed whether any of the ideas we were generating did not fit with the new constructs being considered. Noblitt and Hare (1988) call these "refutational", meaning that they do not fit with the line of argument emerging from the translation process. These refutational constructs can be important because they provide evidence to question the emerging ideas. They reduce the likelihood of the research group making too many assumptions during the process of translation drawing on their own knowledge rather than evidence from the articles. The benefit of having a large research team was that we had the opportunity to challenge each other's possible assumptions. Having thoroughly debated each of the chosen articles there were no refutational constructs emerging from the articles.

Audit

Qualitative researchers have defined a series of strategies for creating a valid and transparent audit trail (Guba & Lincoln, 1989). In this research the coordinating researcher maintained an article trail of all the documentation, the research papers, the draft models created and decisions made during the process of the meta-ethnography. All meeting notes and decisions were recorded and each new set of diagrams and the constructs generated were kept together.

An independent expert in meta-ethnography reviewed the collection and synthesis of the articles and the final results were presented to a second expert.

RESULTS

The process of conducting the meta- ethnography helped us to identify the intensity, the relentless pressure, and the exhaustion that characterizes the twenty-four hour care role particularly where psychological impairment is a feature of the condition. Of note, however, was the fluctuating nature of the emotional impact, varying from day to day and over time. In many of the research articles participants were asked to "describe" emotional impact. However, how that impact was translated into "effect" on the carer was not always emphasized. The benefit of grouping the emotion words relating to carer impact across studies was our increasing understanding of the depth and breadth of the emotional impact and how it varied over time.

As the example given in table two shows the words related to emotion that were used by participants assisted in our understanding of how emotional responses were experienced. The type of framework used in table two was used for further discussion amongst the research team and as a result we identified the 'caring inputs' which related to the efforts made by the carer and support services and the 'responses' arrived at following these caring inputs. We then identified and developed a set of words which represented the 'resulting behavior and experience'. The 'resulting behavior and experience' was formed from the interrelationship between the carer inputs and their individual and/or shared response.

Caring Inputs

Inputs related to the activities the carers performed every day to support the caree over time. The intensity of this activity fluctuated depending on physical and mental deterioration

of the caree and how much support the carer received from family and friends. The key element to these activities was the effect these inputs had on how time was managed.

Time

As the neurological condition progressed, and cognition deteriorated, the idea of time changed. Carers had a different focus to their day and caring duties increased. These caring duties fluctuated with the daily change in cognitive symptoms that sometimes occurred (Chesla *et al*. 1994). Time also offered sense of continuity as each step in deterioration was identified and adapted to. These changes, which began as a dual effort to adjust, increasingly became part of the carer role only (Chesla *et al*., 1994; Birgersson & Edberg, 2004; Cheung & Hocking, 2004; Courts *et al*., 2005; Persson & Zingmark, 2006, Goldsteen *et al*., 2007; Dunham & Cannon, 2008).

Over time the experience also affected the quality of the relationship; with some carers feeling they should protect themselves by becoming emotionally separate (Cheung & Hocking, 2004; Persson & Zingmark, 2006; Vikstrom *et al*., 2008; Williamson *et al*., 2008). Being emotionally separate, or "falling out of love", could be seen as a protective action and might be related to the changing roles, adapting to new challenges and becoming the stronger partner because of it (Hepburn *et al*., 2002: 223). However, it could also be seen as a response to the carer's need to release themselves from the relentlessness of their role (Habermann, 2000; Butcher *et al*., 2001; Hepburn *et al*., 2002).

Carers talked about how they found themselves being a witness to the loss of cognition that left them sometimes feeling sad and at other times overwhelmed by the carees' inability to manage their lives. This increased the iterative nature of loss and hope over time and yet, for some, made them feel a greater sense of marital duty and devotion (Habermann, 2000; Vellone *et al*., 2007; Dunham & Cannon, 2008). Over time carers adapted and found ways to cope, but some reflected on the fact that their lives appeared to be on hold, a time related

expression (Chesla *et al*., 1994; Macrae, 1999; Habermann, 2000; Sanders & McFarland, 2002; Hepburn *et al*., 2002; Mahoney, 2003; Neufeld & Harrison, 2003; Courts *et al*., 2005; Robinson, *et al*., 2005; Persson & Zingmark, 2006; Goldsteen *et al*., 2007; Williamson *et al*., 2008; Williams *et al.*, 2009).

Responses

Responses relate to the effects of the caring activities carried out. How the caree responded to the caring and how their disease affected him or her altered these responses in positive and negative ways. Responses could enhance the quality of life of the carer or create feelings of anger and rejection.

Carer and Caree positive responses

Managing the balance in psychological symptoms appeared to become the focus of the caring role. Taking on more duties was connected with wanting to maintain a high quality of life for the caree and the family (Courts *et al*., 2005; Persson & Zingmark, 2006; Vellone *et al*., 2007) yet was tempered by not wanting to be consumed by the caring role (Habermann, 2000). There was commitment to the caring role whether or not it had been willingly taken on yet dealing with behavior changes was exhausting, scary, and frustrating.

Carers recognized that the caree was trying their best and when they returned affection there was recognition of the reciprocity in the relationship either because of the support that had been provided prior to illness or the efforts made on a daily basis by the carees to manage their lives (Murray *et al*., 1999; Habermann, 2000; Hepburn *et al*., 2002; Sanders & McFarland, 2002; Persson & Zingmark, 2006). Some carers reported the illness as coming as a "blessing" because barriers had been broken and a sense of humor between the couple had grown and developed (Murray *et al*., 1999; Habermann, 2000; Harkness – Hodgson *et al*., 2004; Robinson *et al*., 2005; Persson & Zingmark, 2006; Williams *et al*., 2009). These positive aspects led to increased protectiveness on the part of the carer (Murray *et al*., 1999;

Courts *et al*., 2005) and a renewed commitment to maintain the sense of connection and the effort to stay together (Murray *et al*., 1999; Hepburn *et al*., 2002; Harkness – Hodgson *et al*., 2004; Vellone et al., 2007).

This sense of connection enabled carers to question how they were living their lives and to search for new meaning and understanding of themselves and the nature of their relationship (Chesla *et al*., 1994; Murray *et al*., 1999; Habermann, 2000; Hepburn *et al*., 2002; Sanders & McFarland, 2002; Mahoney, 2003; Birgersson & Edberg, 2004; McKeown *et al*., 2004; Polk, 2005). Given time, some of the carers reflected the fact that they had found joy and new meaning in their lives together with the caree (Murray *et al*., 1999; Birgersson & Edberg, 2004; Courts *et al*., 2005; Persson & Zingmark, 2006; Vikstrom *et al*., 2008). There was evidence that their relationships had been transformed and a new kind of love had developed based on marriage vows and duty on the one hand, and new opportunities for spending more time together on the other (Murray et al., 1999; Haberman, 2000; Hepburn *et al*., 2002; Sanders & McFarland, 2002; Courts *et al*., 2005; Dunham & Cannon, 2008; Persson & Zingmark, 2006).

Carer and Caree negative responses

Carers spoke of their frustration at feeling inadequate to the task of caring (Haberman, 2000; Betts, 2006) at dealing with the symptoms (Haberman, 2000; Polk, 2005) and realizing that they sometimes took those frustrations out on the caree (Vikstom *et al*., 2008). The resulting emotion caused by the frustration was impatience, which could turn to anger (Murray *et al*., 1999; Butcher & Buckwalter, 2002; Boeiji *et al*., 2003; Neufield & Harrison, 2003; Hepburn, 2004; Mckeown *et al*., 2004; Galvin *et al*., 2005; Betts, 2006; Dunham & Cannon, 2008). Carers described how on the one hand they resented the extra burden (Sanders & McFarland, 2002; Boeiji *et al*., 2003; Hepburn, 2004; Scott *et al*., 2005; Betts, 2006) and on the other were left feeling guilty and exasperated about their situation (Hepburn

et al., 2002; Harkness-Hodgson, 2004; McKeown *et al*., 2004; Scott *et al*., 2005; Dunham & Cannon, 2008).

The effect of the everyday management of someone who is less of the person once known appeared to leave carers feeling depressed and neglected (Hepburn *et al*., 2002; Birgersson & Edberg, 2004; Cheung & Hocking, 2004; Goldsteen *et al*., 2007; Dunham & Cannon, 2008; Williams *et al*., 2009). Carers became observers to the loss of their confidant (Butcher *et al*., 2001; Betts, 2006; Dunham & Cannon, 2008), which left them feeling lonely, even when with the caree. The unpredictable behavior meant that previous friends and the social life they had once experienced diminished, with the resulting feelings of isolation (Neufeld & Harrison, 2002; McKeown *et al*., 2004; Williams *et al*., 2009). At home unusual behavior could be tolerated but when in public could cause distress to the carer (Persson & Zingmark, 2006). Thus the emotional impact of behavior varied depending on how it was manifested. Carers talked about having to deal with the "offensive" (Dunham & Cannon, 2008) things said to them and the aggression and demanding behavior of the carees which could be expressed by things from "acting up in public places"(Macrae, 1999:63) to "inappropriate sexual advances" (Sanders & McFarland, 2002:71). These points were substantiated by other participants in studies conducted by Chesla *et al*., 1994; Murray *et al*., 1999; Hepburn *et al*., 2002; Cheung & Hocking, 2004; Harkness – Hodgson *et al*., 2004; Galvin *et al*., 2005; Persson & Zingmark, 2006; Williamson *et al*., 2008. There was general agreement that the "physical things were not as bad as the mental things" (Courts *et al*., 2005:24).

Managing difficult behavior meant a re-negotiation of life. This re-negotiation took several forms but its goal was to regain and maintain some form of normality (McKeown *et al*., 2004). Re-negotiation of both family life and the caring relationship involved shifts in the balance of power, with emphasis on the carer taking on increasing responsibility. The role

reversal was not always greeted with enthusiasm by the person being cared for, making negotiation more difficult and subterfuge was used by the carer on occasion as a tool in caree management (Murray *et al*., 1999; Habermann, 2000; Hepburn *et al*., 2002; Courts *et al*., 2005; Williams *et al*., 2009).

Resulting behavior and experience

The outcomes of long-term caring for a person who was losing touch with reality depended largely on how positive the shared experience was. As has been shown negative behavior could have negative effects on carer and caree alike and would lead to feelings of frustration, exhaustion and disappointment on both sides. However positive reactions from caring behaviours could lead to an enhanced relationship, and joint satisfaction. There appeared to be no way of predicting how long term care would affect the carer and caree, but it appeared, from the research findings across papers, that the quality of the previous relationship was not necessarily a predictor of a reciprocal shared caring nor was the amount of time spent caring, nor was the amount of support available. What appeared to be important was the interrelationship between caring behavior of both the carer and the caree, on the one hand, and their individual and joint responses to that caring over time. The type of response, positive or negative changed the experience of the disease and its effects.,

DISCUSSION

The aims of this meta-ethnography were two fold. The first was to utilize the findings of published qualitative research, related to four common neurological conditions, to develop a deeper understanding of the impact of cognitive impairment on the carer and to find areas of possible concordance across neurological diseases. The second was to provide a worked example of a meta-ethnography.

Emotional impact on carers

Whilst we searched for consistency of interpretation across the thirty one research articles we also looked for contradictions which might lead us to think that cognitive impairment, as a result of one disease, was different to that of another. We found there was marked concordance of carer experience across the four diseases. The similarity was so marked that, during the discussions, the research group ceased to be aware of the patients' diagnosis as they became involved in the in-depth analysis of the carer/caree experience. This decision is important because service providers across Western healthcare systems have focused attention on whether to offer generic care, or disease specific care, for people with neurological diseases (Suddick & De Souza, 2007). The concordance identified in this study would suggest that, where carer support is concerned, many of the problems associated with managing cognitive impairment could be dealt with in mixed disease groups.

The individual articles identified both the relentlessness of care and the struggle to come to terms with symptoms. The majority of papers described the observations by the carers of the psychological and physical deterioration of their loved ones and how these observations affected their ability and willingness to care over time. Following the process of re-interpretation across the studies the results highlighted the intensity and constancy of the emotional impact of dealing with carees with increasing cognitive impairment and, importantly, how the inter-relationship between caring behavior and responses changed behavior and how the disease was experienced over time.

The fluctuating nature of the impairment appears to cause dichotomous responses; feelings of happiness and fulfillment alongside anger and worry. Andren and Elmstahl (2005), in their study of over one hundred and fifty family carers of people with dementia, also describe this mixture of the positive and negative sides of caring and highlight how it is possible to experience both at the same time. The meta-ethnography results concur with the

Andren and Elmstahl research emphasizing the contradictions in the experience of care: the co-existence of sadness and happiness; loving but feeling anger and frustration; controlling but also having to let go.

Kendall *et al*. (2009) have suggested that in order to manage this daily change in mood, and consequent quality of life, a better understanding of the needs of patients and their carers could help to inform the development of health and social care services . As the discussion among research group members developed we were acutely aware of the changes over time due to the fluctuation in mood, ability and memory of the caree, and, more importantly, how the responses to caring would affect both carer and caree. The carer and carees emotions changed from day to day and moment to moment, making time a key component of the caring role. Where one of the partners is losing touch with reality, the degree of mutual caring becomes progressively more limited. It changes the balance of power within the relationship, with men and women carers having to learn new skills.

Many of the findings from the individual research articles are not new to those who investigate the impact of illness on carers (Nolan, 2002; Tooth *et al.*, 2008; Cooper, 2009; McLaughlin *et al.*, 2010). What this meta ethnography adds is further depth and understanding of the emotional impact of psychological and cognitive deterioration on carers. **Re-appraising the set of original studies increases the sample size of the original studies and therefore adds substantial evidence of the emotional impact and how the input/response interrelationship effects the couple's equilibrium and influences the couple's behavior and experience over time. The value of this meta-ethnography is that it supports existing research into carer experience but then offers a greater breadth and depth to the issues being studied than would the findings from individual studies.**

The following model (Fig 1) provides a framework for understanding how carer behaviour affects and is affected by caree response. The concepts identified by the

process of meta-ethnography, using constant comparison across the research papers, have identified how closely the interrelationship between the caring inputs, and the responses of the caree determine the quality of the emotional experience and behavior of both caree and carer.

Insert Figure 1 Model of caring for people with increasing cognitive impairment

Meta-ethnography

Noblit & Hare (1988) point out that answers can only be developed from what is already there in the selected research literature, so rather than developing new ideas meta-ethnography offers a method of re-evaluating existing literature to develop a re-focus or greater understanding of the phenomenon under review. We have added to the literature on meta-ethnography by offering a worked example of the method and a line of argument and Figure 1 offers a new emphasis on the emotional overload of caring for someone with increasing cognitive impairment.

Of great value to this meta-ethnography was the diversity and mixed backgrounds of the research team. This allowed us to challenge ideas that may have been the result of existing knowledge or empirical background and focus only on what we could find to describe and translate in the synthesis articles. However this was also a constraint as the normal workload for senior members of staff meant that meeting together for extended periods of time was difficult to achieve. For this reason it is imperative that one person within the team take the major share of the organization and development of the synthesis documents and the preparation of materials before each meeting.

The translation/reinterpretation process is key to meta-ethnography and it is important to develop various methods of presenting the information gathered developing charts, maps

and tables which begin the process of understanding the fit of the constructs being developed. It is recognized that the process of deciding on the choice of participant quotes and primary research categories is subjective, as is the development of the synthesis and translation (Sandelowski & Barroso, 2007; Malpass *et al*., (2009). However it is hoped that the diversity of the team, who were ready to challenge ideas and discussion points as they emerged, enhanced the validity of the process. The process and findings were discussed with an independent, experienced researcher in meta-ethnography at all stages.

CONCLUSION

This meta-ethnography has confirmed the extent of the impact of the emotional burden of caring for people with increasing cognitive impairment. Providing psychological support, recognizing the positive and negative combinations of experience early, might help health and social care workers to prepare family carers for the benefits and difficulties of caring. If health and social care workers are aware of the inter-relationship between how much time the carer cares, and the importance of receiving a positive response from the caree, then care might be planned which prepares families for what is to come and this, in turn may reduce some of the negative responses of both carer and caree. The goal of care would be to enable positive outcomes in terms of experience and behaviour.

Across the Western world and in response to an aging demographic Governments health and social care strategies recognize the need to see the value family based care and support for carers. Yet these plans tend to focus on management systems and devolving to local decision making. Using a meta-ethnography method has allowed greater understanding of the interrelationship between caring, the response to caring and how this response affects behavior over time. This greater depth of explanation of the facets of the caring relationship may help to plan care in a constantly changing context. Effectively managing increasing

cognitive impairment in a changing environment needs a higher priority when planning support.

DISSEMINATION

The method and results have been presented at a UK based University methods meeting, the British Gerontological Society Conference and the International Qualitative Methods Conference at the University of Alberta, Vancouver, Canada.

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